

Dear Senator Crisco and Fontana,

Thank you very much for letting me submit my testimony in support of house bill 5009 legislation to mandate insurance companies to pay for the cost of bone marrow registration. My name is Danny Lemos and in Jan. 2005 I was diagnosed with Lymphoma.

We were all shocked because neither side of my family has a history of cancer. My Dr. at Dana Farber said the best chance for a full cure would be a bone marrow stem cell transplant from an adult donor. Cord blood was also an option but there were even few of those available.

He told me that they would begin testing family members but there was only a 25% chance to find a match in my family so they would also be checking the world bone marrow registry for a match. I started Chemo that night and awaited the news for a potential bone marrow match. About a week later I received the bad news that my neither my brother nor cousins were a close enough match and no one on the world registry were matches either.

I thought that I was a rare case but in fact the Dr's told me that this was very common. There were just not enough people on the bone marrows registries. World wide there are only 10 million people on the registry and less than half will go through the process. The dr's told me that they were sure there were many perfect bone marrow matches for me out there but just not enough people register. If I had found a match I had about an 80 to 90 % chance of curing my cancer. Without a match I had about an 80 to 90 % chance that this cancer would take my life within a few years. My Dr's put me in contact with the national marrow donor program out of Minnesota.

This organization helps people like me hold bone marrow drives so we can find a match that can help up cure our cancers. We started doing bone marrow drives in ct. But very few people came. It cost about \$ 55.00 to test each person and many people especially the people that you want on the registry men and women between they ages of 18 to 45 could not afford to pay for the tests.

I thought it was ridiculous that the insurance companies did not cover the cost of these tests. It was like having the Red Cross ask you to donate a pint of blood but charging \$55.00 for your trouble.

The Insurance companies would pay for millions of dollars for drugs each year to keep me alive for a few years but would not cover the \$55.00 to help find my cure? So we started to advertise that the cost for testing would be covered. Cancer is bad enough on the patient and their family.

We started funding these bone marrow drives ourselves. My out of pocket cost has been in the tens of thousands of dollars. We've gone through all our life's savings and most of our children's college funds. I had to go on disability for a year it ruined us financially.

A few months after being on 8 cycles of CHOP chemo my cancer returned. So I went on 3 cycles of ICE chemo and my only option was to do a bone marrow transplant using my own cells. Which was completed in April 2006.